

ORIGINAL

*K8 / "DUKE"

PUBLIC HEALTH AND PRIVATE ETHICS

AN ADDRESS BY
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PRESENTED TO THE ROUND TABLE ON SCIENCE AND PUBLIC AFFAIRS
DUKE UNIVERSITY
DURHAM, NORTH CAROLINA
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(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

I'M PLEASED AND HONORED TO BE YOUR LECTURER THIS EVENING AS PART OF THIS IMPORTANT PROGRAM. IT WAS EASY TO SAY "YES" TO ALEX ROLAND'S KIND INVITATION LAST SPRING. OF COURSE I WOULD WANT TO BE A PART OF THIS SERIES.

BUT SINCE THEN I'VE BEEN THINKING ABOUT WHAT IT IS I HAVE TO SAY ...AND I'VE BEEN TRYING TO FACE THAT CHALLENGE NOW FOR WEEKS.

IT ISN'T THAT I'M AT A LOSS FOR WORDS. NO ONE WOULD BELIEVE THAT ANYWAY. RATHER, I FIND IT DIFFICULT TO IDENTIFY THE PLACE TO START IN MY DISCUSSION TONIGHT OF "PUBLIC HEALTH AND PRIVATE ETHICS." SO MUCH HAS HAPPENED, SINCE MY LETTER WENT BACK TO ALEX ROLAND ACCEPTING HIS KIND INVITATION:

- * SEVERAL OTHER INDIVIDUALS HAVE RECEIVED BOTH ARTIFICIAL AND HUMAN HEARTS...AND MANY HUNDREDS HAVE RECEIVED A VARIETY OF OTHER REPLACEMENT ORGANS...
- * RESEARCHERS HAVE GOTTEN A LITTLE BIT CLOSER, I AM GIVEN TO BELIEVE, TO THE SOURCE OF THE PUZZLE WE CALL "ACQUIRED IMMUNE DEFICIENCY DISEASE," OR AIDS...
- * FOUR NEW WARNINGS FROM THE SURGEON GENERAL ARE NOW APPEARING ON CIGARETTE PACKAGES AND IN ALL CIGARETTE ADVERTISING AND PROMOTION...
- * SOMETHING CALLED "GRAMM-RUDMAN-HOLLINGS" IS CHANGING THE WAY WE CAN INVEST IN MANY AREAS OF HEALTH AND HUMAN SERVICES, AND WE ARE TRYING TO ADJUST OUR THINKING TO THIS SITUATION...

- * AND THE WHOLE WORLD SAW SEVEN EXTRAORDINARY AMERICAN SCIENTISTS BLOW UP LESS THAN 10 MILES ABOVE THE ATLANTIC OCEAN, AND WE'RE TRYING TO FIND OUT WHY.

IN OUR SOCIETY, OF COURSE, SCIENCE IS A PUBLIC AFFAIR. PUBLIC HEALTH IS A PUBLIC AFFAIR. BUT SAYING THAT DOESN'T ANSWER ANY QUESTIONS. QUITE THE CONTRARY, IT RAISES MANY NEW QUESTIONS TO PONDER.

THIS EVENING, I WANT TO TALK A LITTLE BIT ABOUT ONE OF THE HARDEST QUESTIONS WE FACE, NOW AND TOMORROW. IT'S A SIMPLE QUESTION AND IT GOES LIKE THIS:

"WE CAN DO IT...BUT IS IT THE RIGHT THING TO DO?"

A SIMPLE QUESTION TO ASK...BUT THE MOST DIFFICULT OF ALL TO ANSWER.

AFTER ALL THE LEGAL CITATIONS AND THE FOOTNOTES AND FOREWORDS AND APPENDICES, EACH OF US WILL PROVIDE AN ANSWER THAT IS ESSENTIALLY DRAWN FROM DEEP WITHIN OUR OWN CONSCIENCES...THAT REFLECTS THE WAY WE WERE BROUGHT UP AND WHERE WE WERE BROUGHT UP...AND PLACES US ON THE SIDE OF PEOPLE WHO THINK THE SAME WAY WE DO...PEOPLE WE LIKE AND WHO WE WISH WOULD LIKE US.

NOTICE I HAVE NOTHING TO SAY ABOUT WHETHER OR NOT THE PRICE IS RIGHT. AND I ALSO REJECT OUT OF HAND ANY NOTION THAT WE SHOULD DO DOING WHAT IS RIGHT IF THE POLITICS IS RIGHT.

AFTER FOUR YEARS AS YOUR SURGEON GENERAL, AND ALREADY STARTING ON MY SECOND FOUR-YEAR TERM, I CAN HONESTLY TELL YOU THAT, WHEN DECISION TIME COMES AROUND IN PUBLIC HEALTH, WE TEND TO OPERATE AT THE LEVEL OF CONSCIENCE, OF HERITAGE, OF FAMILY...IN SHORT, AT THE LEVEL OF WHAT IS CALLED ONE'S "ETHICS."

SEVERAL WEEKS AGO, MY LECTURE FOR THIS EVENING SEEMED TO BE IN GOOD ENOUGH SHAPE, ALTHOUGH IT SOMEHOW STILL LACKED THAT STARTING-POINT. AND THEN, AS I WATCHED PRESIDENT REAGAN DELIVER HIS ADDRESS ON THE "STATE OF THE UNION," THE STARTING-POINT BECAME QUITE CLEAR.

I'M GOING TO START WITH THE OVERALL ISSUE OF THE AMERICAN FAMILY ... WHAT WE ARE DOING FOR IT OR TO IT...AND WHAT WE EXPECT FROM IT. I HAPPEN TO SHARE WITH THE PRESIDENT THE FEELING THAT THE FAMILY IS THE FUNDAMENTAL UNIT OF STRENGTH IN OUR SOCIETY. AS SUCH, IT NEEDS OUR MOST THOUGHTFUL ATTENTION.

SOMETIMES WE DO WELL BY THE FAMILY AND SOMETIMES WE MAKE ITS LIFE MUCH HARDER. ODDLY ENOUGH, WE USUALLY DO BOTH KINDS OF THINGS IN THE NAME OF SOME "HIGHER ETHIC."

I THINK WE ARE SINCERE, BUT WE'RE ONLY HUMAN. HENCE, EVERY NOW AND THEN WE PROBABLY OUGHT TO TAKE A MOMENT TO EXAMINE CRITICALLY JUST WHAT IT IS WE'RE DOING ABOUT THE AMERICAN FAMILY IN THE NAME OF ETHICS.

AND TONIGHT SEEMED TO OFFER A MOST IDEAL MOMENT INDEED.

LET ME BEGIN WITH TWO EXAMPLES OF PUBLIC HEALTH ISSUES WITH WHICH I WAS INTIMATELY INVOLVED AND WHICH HAVE HAD A SIGNIFICANT IMPACT ON THE FAMILY. THEY EACH POSED A SIGNIFICANT ETHICAL QUESTION AND EACH QUESTION HAS BEEN ANSWERED IN A SPECIAL WAY.

BOTH THESE ISSUES ARE POPULARLY RECOGNIZED IN THE PUBLIC MIND NOT BY ANY SPECIAL HEADLINE CODE-WORDS, BUT RATHER BY THE NAMES OF THE CHILDREN WHO WERE INVOLVED: THE FIRST ONE WAS "KATIE BECKETT"...THE SECOND ONE WAS "BABY DOE."

IN SOME WAYS THE "KATIE BECKETT" EXAMPLE IS A CLASSIC CASE. IN 1981 KATIE BECKETT WAS THREE YEARS OLD AND IN A HOSPITAL IN HER HOMETOWN OF CEDAR RAPIDS, IOWA. SHE WAS RECOVERING FROM A SERIOUS CASE OF VIRAL ENCEPHALITIS. KATIE WAS BEING MAINTAINED ROUND-THE-CLOCK BY RESPIRATOR THERAPY.

THE BECKETTS MADE THE ROUND-TRIP BETWEEN THEIR HOME AND THE HOSPITAL EVERY DAY AND SOMETIMES SEVERAL TIMES A DAY. THEY DID NOT WANT KATIE TO FEEL ABANDONED. THEY WANTED TO KEEP THE BOND BETWEEN THEM OF FAMILY LOVE JUST AS STRONG AS POSSIBLE.

GOVERNMENT RULES SAID SHE COULD ONLY RECEIVE RESPIRATOR THERAPY IN THE HOSPITAL, IF IT WAS TO BE PAID FOR BY GOVERNMENT FUNDS. IT WAS...AT A MONTHLY COST \$12,000.

I DIDN'T THINK THE SITUATION MADE ANY SENSE. I KNEW FROM PERSONAL EXPERIENCE THAT CHILDREN RESPOND BETTER TO THERAPY IF THEY'RE IN THE CARE OF THEIR FAMILIES.

OF COURSE, MOST FAMILIES ARE NOT SKILLED IN MEDICINE. IN FACT, MOST FAMILIES HAVE A LONG WAY TO GO IN MANY MATTERS OF PUBLIC HEALTH. AND THE BECKETTS WERE NOT ALL THAT DIFFERENT. BUT WHAT THEY LACKED IN MEDICAL EXPERTISE THEY MADE UP FOR IN LOVE AND COMPASSION.

NOW, IF YOU WANT TO TALK ABOUT AUTHENTIC MIRACLE-WORKING THERAPIES, I'D LIKE TO SUGGEST THAT "LOVE" AND "COMPASSION" ARE RIGHT UP THERE AT THE TOP OF THE LIST...ALONG WITH CHICKEN SOUP.

FORTUNATELY, PRESIDENT REAGAN FELT THE SAME WAY. IN NOVEMBER OF 1981 HE INSTRUCTED THE PEOPLE IN HIS ADMINISTRATION TO STRAIGHTEN OUT THIS AFFAIR.

I WAS THE PRESIDENT'S NEWEST "KID ON THE BLOCK," HAVING JUST BEEN CONFIRMED BY THE SENATE AS HIS SURGEON GENERAL. I WAS DELIGHTED TO BE ABLE TO ATTACK THIS PARTICULAR PROBLEM AS MY FIRST BIG ASSIGNMENT IN THE U.S. PUBLIC HEALTH SERVICE.

I'M PLEASED TO SAY THAT WITHIN A MATTER OF MONTHS WE WERE ABLE TO PROVIDE THE BECKETT FAMILY WITH A WAIVER, SO THAT THEY COULD TAKE KATIE HOME AND HAVE THE NECESSARY RESPIRATORY THERAPY, TOO.

ODDLY ENOUGH, THE COST OF HOME CARE CAME DOWN TO LESS THAN \$1,000 A MONTH, OR MORE THAN \$11,000 LESS THAN THE COSTS UNDER THE OLD RULES.

THE DEVELOPMENT WAS SO SIGNIFICANT THAT OUR DEPARTMENT OF HEALTH AND HUMAN SERVICES SET UP A "KATIE BECKETT REVIEW BOARD" TO SOLVE OTHER CASES JUST LIKE HERS, AND THERE WERE QUITE A FEW OF THEM. I BECAME THE CHAIRMAN OF THAT BOARD FOR TWO YEARS. DURING THAT PERIOD WE PROVIDED RELIEF TO THE FAMILIES OF NEARLY 100 OTHER CHILDREN WITH A VENTILATOR-DEPENDENCY LIKE KATIE'S.

THERE IS YET ANOTHER SIDE TO THIS STORY. VENTILATOR-DEPENDENCY AT HOME, WHILE DESIRABLE, IS NEVERTHELESS A COMPLICATED MEDICAL PROBLEM:

YOU NEED OXYGEN TANKS AND OTHER EQUIPMENT DELIVERED TO HOMES BY PRIVATE SUPPLIERS. YOU HAVE TO WORK OUT THE SCHEDULES, ARRANGE BACK-UP ROUTINES FOR EMERGENCIES, AND SO ON...

YOU ALSO NEED THE HELP OF ONE OR SEVERAL COMMUNITY-BASED SERVICE GROUPS, SUCH AS HOME NURSING CARE FOR THE PATIENT AND COUNSELING AND RESPITE CARE FOR THE FAMILY...

YOU NEED GOOD ADVICE TO MAKE SURE ALL THE COSTS ARE COVERED EITHER BY FEDERAL OR STATE PROGRAMS OR, WHERE POSSIBLE, BY PRIVATE INSURANCE...

AND YOU NEED A HOSPITAL STAFF WHO WILL RETAIN PROFESSIONAL RESPONSIBILITY FOR THE COURSE OF THERAPY, WHO WILL NOT, AS IT WERE, "ABANDON" THEIR VENTILATOR-DEPENDENT PATIENTS, WHEN THEY GO HOME.

WHILE WE WERE PUTTING TOGETHER THE MACHINERY TO TAKE CARE OF KATIE BECKETT, IT SEEMED TO ME THAT WE OUGHT TO USE THE EXPERIENCE AS A WAY OF LEARNING HOW TO HANDLE CHILDREN WITH OTHER HANDICAPPING CONDITIONS, ALSO.

ONE YEAR AFTER RECEIVING MY MARCHING ORDERS FROM THE PRESIDENT, I CONVENED A "SURGEON GENERAL'S WORKSHOP ON HANDICAPPED CHILDREN AND THEIR FAMILIES." THE PROBLEM OF VENTILATOR-DEPENDENCY WAS A CENTRAL TOPIC, TO BE SURE. HOWEVER, I LEFT PLENTY OF ROOM ON THE AGENDA FOR DISCUSSIONS OF OTHER HANDICAPPING CONDITIONS AS WELL.

I LOOK BACK ON THAT WORKSHOP WITH A GREAT DEAL OF PRIDE. IT STIMULATED A WHOLE NEW WAVE OF THOUGHT AND ACTION IN RESPECT TO THE WAY WE CARE FOR HANDICAPPED CHILDREN AND THE FAMILIES.

THERE HAVE BEEN 14 REGIONAL CONFERENCES AFTER THAT ONE WORKSHOP. THEY'VE DEALT CREATIVELY WITH THE PROBLEMS FACED BY FAMILIES OF PATIENTS WITH SUCH CONDITIONS AS...

MUSCULAR DYSTROPHY...HEMOPHILIA...ARTHRITIS...SEIZURE DISORDERS... JUVENILE DIABETES...CYSTIC FIBROSIS...LANGUAGE DYSFUNCTION...DOWN SYNDROME...AND A RANGE OF MILD TO SEVERE SENSORY DEFICITS AND EMOTIONAL DISORDERS.

IN THAT SONG, "NEW YORK, NEW YORK," FRANK SINATRA SAYS, "IF I CAN MAKE IT THERE, I'LL MAKE IT ANYWHERE." THAT'S EXACTLY HOW I FELT AT THAT WORKSHOP: IF WE COULD "MAKE IT" WITH VENTILATOR-DEPENDENCY, WE COULD "MAKE IT" WITH ANY DISABLING CONDITION.

AND WE DID.

AFTER TWO YEARS, THE KAITGE BECKETT BOARD WASN'T NEEDED ANYMORE, BECAUSE THE MEDICARE AND MEDICAID RULES WERE CHANGED. TODAY, EVERY VENTILATOR-DEPENDENT CHILD WHO POSSIBLY CAN, IS NOW RELEASED TO HIS OR HER FAMILY WHERE THE ULTIMATE CURE FOR ALL PERSONAL ILLS RESIDES: THAT IS, FAMILY LOVE.

BEFORE LEAVING THE STORY OF KATIE BECKETT, LET ME JUST UNDERSCORE ONE POINT:

UP TO THE TIME THE BECKETTS COMPLAINED, THE GOVERNMENT WAS WILLING TO GO ON PAYING BIG MONEY ACCORDING TO ITS OWN NARROW RULES. AND, REMEMBER, THE MONEY WAS THERE TO BE PAID. SO INITIALLY MONEY WAS NOT THE ISSUE. AND I MAINTAIN THAT MONEY IS STILL NOT THE ISSUE IN THE REALLY DIFFICULT HUMAN CASES.

NO, THE QUESTION WAS...SHOULD WE KEEP THIS CHILD, KATIE BECKETT, IN THE HOSPITAL AND AWAY FROM HER FAMILY, WHICH IS THE ALL-TOO-TYPICAL RESPONSE OF OUR MEDICAL TECHNOCRACY, OR IS THERE ANOTHER, BETTER WAY TO TREAT HER CONDITION...A WAY THAT IS RIGHT FOR THAT FAMILY?

I BELIEVE WE FOUND THE BETTER WAY.

I SAID A MOMENT AGO THAT -- EVEN WITH THEIR LIMITED MEDICAL KNOWLEDGE -- MOST FAMILIES OFFER THE ULTIMATE THERAPY FOR A GREAT MANY OF THE ILLS OF CHILDREN: THAT IS, LOVE AND COMPASSION.

YET, I MUST ADMIT THAT THIS, TOO, MAY BE ONE OF THOSE RULES THAT IS PROVED BY THE EXCEPTION. AND THE EXCEPTION APPEARED IN BLOOMINGTON, INDIANA, IN EARLY APRIL OF 1982.

A BABY BOY WAS BORN THERE WITH AN OBSTRUCTION OF ITS ESOPHAGUS. NOW, THAT KIND OF THING CAN BE CORRECTED THROUGH SURGERY. I'VE DONE IT MANY, MANY TIMES. OTHERS HAVE, TOO.

BUT "BABY DOE" ALSO HAD DOWN SYNDROME, A FORM OF MENTAL RETARDATION. WAS IT BAD? WE DON'T KNOW AND WE'LL NEVER KNOW IF "BABY DOE" WAS MILDLY OR SEVERELY RETARDED...IF HE WOULD HAVE GROWN TO BECOME AN ADJUSTED, HAPPY, SELF-SUPPORTING CITIZEN POSSIBLY WITH HIS OWN FAMILY SOME DAY...OR WHETHER HE WAS GOING TO BE A LIFE-LONG PUBLIC CHARGE.

WE DON'T KNOW.

"BABY DOE'S" PARENTS WOULD NOT PERMIT THE SURGERY TO BE PERFORMED ON HIS ESOPHAGUS. HENCE, HE COULD TAKE NO NOURISHMENT...AND 4 DAYS LATER..."BABY DOE" WAS DEAD.

A GROUP OF PHYSICIANS AT THE BLOOMINGTON HOSPITAL HAD STRONGLY DISAGREED WITH THE PARENTS AND WITH ONE OF THEIR COLLEAGUES WHOSE ADVICE APPARENTLY WEIGHED HEAVILY IN THE PARENTS' DECISION. THESE PHYSICIANS TRIED TO HAVE THE COURTS ORDER THE HOSPITAL TO DO THE CORRECTIVE SURGERY, DESPITE THE PARENTS.

THE SUPREME COURT OF INDIANA DID RULE -- FOR THE FIRST TIME EVER, TO MY KNOWLEDGE -- THAT "BABY DOE'S" PARENTS DID HAVE THE RIGHT TO WITHHOLD TREATMENT AND NOURISHMENT FOR THEIR CHILD. THIS DECISION WAS ON APPEAL TO THE U.S. SUPREME COURT, WHEN "BABY DOE" DIED...AND THE CASE WAS THEN MOOT.

THE FUNDAMENTAL ISSUE, AS I SAW IT, WAS THIS:

THE MOMENT "BABY DOE" WAS BORN, HE WAS A FULL CITIZEN OF THIS COUNTRY AND SHOULD HAVE BEEN GIVEN ALL THE CONSTITUTIONAL PROTECTIONS THAT ANY CITIZEN ENJOYS. HE HAD A RIGHT TO LIFE, LIBERTY, AND THE PURSUIT OF WHATEVER LEVEL OF HAPPINESS HE WAS ABLE TO ACHIEVE.

BUT DID "BABY DOE" IN FACT RECEIVE ALL THE PROTECTION HE NEEDED FROM HIS PARENTS, HIS DOCTOR, AND HIS HOSPITAL? NO, I DON'T THINK HE DID. IN FACT, HIS LIFE WAS ENDANGERED...AND FINALLY WAS ALLOWED TO EXPIRE.

"BABY DOE" COULDN'T SWALLOW. HE COULDN'T TALK...HE COULDN'T ARGUE OR PLEAD HIS CASE ON TELEVISION. HE COULDN'T WRITE ELOQUENT LETTERS TO NEWSPAPERS. HE COULDN'T HIRE AN AGGRESSIVE TRIAL LAWYER TO SAVE HIS LIFE.

AND HIS PARENTS WOULDN'T DO ANY OF THESE THINGS.

BY NOW MOST OF YOU HAVE READ THE NEWSPAPER ACCOUNTS OR HAVE HEARD THE ARGUMENTS PRO AND CON ABOUT THE SO-CALLED "BABY DOE" ISSUE. IT HAS BEEN RESOLVED, MORE OR LESS, BY AN ACT OF CONGRESS. FOLLOWING THE INTENT OF THAT LAW, OUR DEPARTMENT HAS PUBLISHED GUIDELINES FOR THE ESTABLISHMENT IN EACH HOSPITAL OF A "PATIENT CARE REVIEW COMMITTEE," WHICH WOULD MAKE THE LIFE-OR-DEATH DECISIONS IN THESE CASES RIGHT THERE ON THE SPOT.

IN OTHER WORDS, THE CONGRESS HAS SAID THAT -- IN CASES INVOLVING THE LIFE OF A NEWBORN, HANDICAPPED CHILD -- THE PUBLIC ETHIC MAY BE MORE RELIABLE THAN THE PRIVATE, PARENTAL ETHIC.

I SUPPORTED THAT SOLUTION AND I WAS JOINED BY A NUMBER OF MY COLLEAGUES IN MEDICINE. BUT LET ME BE ABSOLUTELY HONEST WITH YOU. I DON'T THINK IT'S THE MOST COMFORTABLE SOLUTION FOR OUR SOCIETY.

A FRIEND OF MINE SAID AT THE TIME THAT "THIS LAW MAY SAVE THE BABY, BUT IT CAN KILL THE FAMILY."

IN OTHER WORDS, THE LIFE OF THE BABY IS SAVED, BUT THE NEEDS OF THE FAMILY -- THAT IS, THE PERCEPTION BY THE MOTHER AND FATHER OF WHAT THEIR LIFE TOGETHER IS ALL ABOUT -- THAT MAY SIMPLY BE SET ASIDE AS NO LONGER RELEVANT.

LET ME REPEAT, I STILL THINK THE LAW IS A GOOD ONE AND, IN ANY CASE, I'VE TAKEN AN OATH TO UPHOLD IT. BUT I ALSO KNOW THAT, FOR SOME FAMILIES, THE IMPLICATIONS OF THE LAW COULD BE RATHER STARK.

THE TWO EXAMPLES I'VE JUST GIVEN -- OF "KATIE BECKETT" AND "BABY DOE" -- SET OUT THE BASIC ISSUES, I BELIEVE, ALTHOUGH THEY ARE EXAMPLES OF PROBLEMS AFFECTING RELATIVELY FEW INDIVIDUALS. I DO NOT SUBSCRIBE TO THE NOTION THAT YOU HAVE TO HAVE A CERTAIN NUMBER OF PEOPLE IN PAIN -- A "CRITICAL MASS," AS THE PHYSICISTS WOULD SAY -- BEFORE YOU CAN PAY ATTENTION TO THEIR COMPLAINT.

I STILL FUNCTION AS I DID WHEN I WAS IN PRACTICE: THAT IS, I HAD HUNDREDS AND HUNDREDS OF PATIENTS, BUT I HAD THEM ONE AT A TIME.

BUT IF YOU ARE CONCERNED ABOUT NUMBERS, THEN LET ME GIVE A THIRD EXAMPLE OF AN ETHICAL POSITION THAT IS BEING TRANSLATED INTO PUBLIC HEALTH POLICY AND PUBLIC LAW. THIS IS THE ISSUE OF FAMILY VIOLENCE, AND I AM THE SURGEON GENERAL THAT SAID, BACK IN 1984, THAT VIOLENCE WAS A PUBLIC HEALTH PROBLEM AND THOSE OF US IN HEALTH AND MEDICINE HAD BETTER START DEALING WITH IT.

VIOLENCE CLAIMS AN ESTIMATED 4 MILLION VICTIMS OF CHILD ABUSE AND NEGLECT EACH YEAR. THE DEPARTMENT OF JUSTICE SAYS ANOTHER 1.3 MILLION ADULTS ARE REPORTED AS VICTIMS OF VIOLENT CRIME.

OUR OWN PUBLIC HEALTH SERVICE GROUP CONCERNED WITH THE EPIDEMIOLOGY OF VIOLENCE HAS RESEARCH SHOWING THAT FOR EVERY ADULT VICTIM OFFICIALLY COUNTED BY THE POLICE, AS MANY AS THREE MORE ADULT VICTIMS ARE TREATED AT HOSPITALS BUT ARE MISSED BY THE POLICE.

THE FINAL ESTIMATE OF ALL VICTIMS -- YOUNG AND OLD, REPORTED AND UNREPORTED -- IS CLOSE TO 9 MILLION OF OUR CITIZENS.

SINCE MOST VICTIMS ARE NOT KILLED -- THERE ARE ACTUALLY FEWER THAN 25,000 HOMICIDES A YEAR -- THE OVERWHELMING MAJORITY OF THESE 9 MILLION VICTIMS ARE SURVIVORS, BUT THEY MAY BE PERMANENTLY MAIMED IN SOME WAY...PHYSICALLY, MENTALLY, OR EMOTIONALLY.

THEY ARE OUR CHILDREN, OUR WIVES, AND OUR PARENTS.

IN FACT, ONE OF THE MORE DISTURBING ASPECTS OF FAMILY VIOLENCE IN THIS COUNTRY IS THE RISE IN THE INCIDENCE OF ABUSE AGAINST THE ELDERLY.

LATE LAST YEAR, IN OCTOBER 1985, I CALLED TOGETHER ABOUT 150 NATIONALLY KNOWN EXPERTS IN PUBLIC HEALTH, LAW, MEDICINE, NURSING, AND SOCIAL SERVICES TO SEE IF WE COULD POINT THE PUBLIC HEALTH COMMUNITY IN A NEW AND MORE PRO-ACTIVE DIRECTION ON THIS MATTER OF INTERPERSONAL VIOLENCE...AND FAMILY VIOLENCE IN PARTICULAR. ONCE AGAIN, I USED THE TECHNIQUE OF THE "WORKSHOP."

WE MET FOR TWO VERY INTENSE DAYS AND NIGHTS. AT THE END OF THAT TIME, THE PARTICIPANTS CAME FORTH WITH 153 RECOMMENDATIONS TOUCHING ON PUBLIC AND PROFESSIONAL EDUCATION, RESEARCH, AND THE DELIVERY OF SERVICES.

MARITAL RAPE IS A FELONY IN 28 STATES AND THE DISTRICT OF COLUMBIA. IT OUGHT TO BE A FELONY IN ALL STATES. NORTH CAROLINA, BY THE WAY, IS STILL AMONG THOSE STATES THAT HAVE YET TO ACT IN THIS MATTER.

I WON'T GIVE THE LEGAL ARGUMENTS ONE WAY OR THE OTHER, I JUST WANT TO INDICATE THAT, WHILE MOST STATES HAVE CONFRONTED MARITAL RAPE FOR THE CRIME OF VIOLENCE THAT IT IS, 22 STATES HAVE NOT. IN OTHER WORDS, THERE IS STILL MUCH AMBIVALENCE IN OUR SOCIETY ON THIS MATTER, WHETHER WE LIKE IT OR NOT.

ABOUT 4 MILLION CHILDREN A YEAR ARE ABUSED IN SOME WAY. UNDER FEDERAL AND STATE LAW -- INCLUDING NORTH CAROLINA STATE LAW -- CHILD ABUSE AND CHILD SEXUAL ABUSE ARE ALSO CRIMINAL ACTS. IN ADDITION, ANY PERSON IN THE HEALTH AND SOCIAL SERVICES WHO SUSPECTS THAT A CHILD HAS BEEN ABUSED, MUST REPORT THAT SUSPICION TO THE STATE CHILD PROTECTIVE SERVICES.

FAILURE TO REPORT ANY ACTUAL OR SUSPECTED ABUSE OF A CHILD IS USUALLY PUNISHABLE BY A FINE AND/OR JAIL, ACCORDING TO MOST STATE LAWS, ALTHOUGH THIS IS RARELY DONE. THE REAL PUNISHMENT IS -- OR AT LEAST OUGHT TO BE -- ONE'S OWN CONSCIENCE.

NORTH CAROLINA IS ONE OF JUST SIX STATES THAT REQUIRES EVERYONE WITH KNOWLEDGE OF -- OR SUSPICIONS OF -- A CASE OF CHILD ABUSE TO REPORT THAT TO THE AUTHORITIES. WHILE THE LAW SAYS EVERYONE MUST REPORT, THERE IS NO PENALTY IF YOU DON'T.

I MIGHT ADD THAT THE PHYSICIANS OF BLOOMINGTON, INDIANA, WHO WENT TO COURT ON BEHALF OF "BABY DOE," DID SO UNDER THE PROVISIONS OF THEIR OWN INDIANA CHILD ABUSE LAW.

MANY PEOPLE WHO WORK IN CHILD PROTECTION WOULD LIKE THE LEVEL OF SUSPECTED CHILD ABUSE REPORTING TO BE MUCH HIGHER THAN IT IS. AND I FRANKLY THINK THAT SOME PHYSICIANS LOOK UPON THIS NEW OBLIGATION AS AN INVASION OF THE PRIVILEGED "DOCTOR-PATIENT RELATIONSHIP." I DON'T AGREE WITH THEM, BUT I'M SURE THIS IS A FACTOR WITH SOME.

I MENTIONED THAT THE EXPERTS WHO CAME TO MY "SURGEON GENERAL'S WORKSHOP ON VIOLENCE AND PUBLIC HEALTH" WERE INCLINED TO TAKE A MORE PRO-ACTIVE POSITION ON THE PROTECTION. AND, INDEED, MANY OF THEIR RECOMMENDATIONS WOULD, IN EFFECT, APPLY ON BEHALF OF ADULT WOMEN AND ELDERLY PEOPLE THE SAME LIFE-PROTECTION ETHIC WE NOW APPLY -- BY LAW -- ON BEHALF OF CHILDREN.

WOULD THIS BE A GOOD THING FOR ABUSED WOMEN AND THE ELDERLY? IT OBVIOUSLY WOULD.

WOULD THIS BE A GOOD THING FOR THE PUBLIC HEALTH? YES, I BELIEVE SO, BECAUSE IT COULD REDUCE THE TERRIBLE, UNFAIR BURDEN OF DISABILITY AND PREMATURE DEATH THAT WOMEN AND THE ELDERLY NOW BEAR AND FOR WHICH ALL SOCIETY ULTIMATELY PAYS.

WOULD IT BE GOOD FOR THE FAMILY?

NOW, THE ARGUMENT HAS PROGRESSED TO THE POINT THAT SUCH A QUESTION IS ALMOST IRRELEVANT. AND I THINK THAT POINTS TO WHAT IS GOING TO BE OUR CENTRAL ETHICAL ISSUE IN THE YEARS AHEAD:

IN OTHER WORDS, THE FAMILY IN OUR SOCIETY -- AND HUMAN BEHAVIOR GENERALLY -- MORE AND MORE MUST SATISFY THE REQUIREMENTS OF THE ETHICS OF THE LARGER SOCIETY, RATHER THAN THE REVERSE.

I NEEDN'T REMIND YOU THAT FOR MANY YEARS -- A CENTURY OR MORE -- THE SITUATION WAS THE REVERSE. THE COUNTRY ASKED RELATIVELY LITTLE OF ITS FAMILIES AND ITS INDIVIDUAL CITIZENS, LEAVING MOST ETHICAL JUDGEMENTS TO BE MADE AT HOME. BUT, AS I SAY, THAT'S CHANGING.

MAYBE THINGS HAVE BEEN GOING THE OTHER WAY BECAUSE SUCH ETHICAL LAISSEZ-FAIRE IS NO LONGER ADEQUATE TO THE NEEDS OF OUR MODERN SOCIETY.

I DON'T KNOW ALL THE REASONS FOR THE SHIFT. I DON'T KNOW IF ANY SINGLE PERSON CAN REALLY UNDERSTAND EVERYTHING THAT IS AT WORK IN THIS ISSUE. BUT I DO KNOW THAT IT'S NOT COMFORTABLE FOR US.

I ONCE HEARD THE DEFINITION OF A "NEO-CONSERVATIVE" AS "A LIBERAL WHO WAS MUGGED BY REALITY." BUT, COME TO THINK OF IT, ALL OF US, REGARDLESS OF OUR IDEOLOGIC LABELS, HAVE BEEN "MUGGED BY REALITY" IN THE SENSE THAT WE'VE FOUND THAT "RUGGED INDIVIDUALISM" CAN BE DANGEROUS TO SOMEBODY'S HEALTH AND THAT THE ETHICS OF THE STATE CAN INTRUDE INTO THE DEEPEST CORNERS OF ONE'S HOME.

AM I SOUNDING SOME KIND OF AN ALARM TONIGHT? NO, I'M NOT THAT THEATRICAL. WHAT I'M REALLY DOING IS SHARING WITH YOU A PERCEPTION OF THE BALANCING ACT WE CARRY ON -- WHETHER WE KNOW IT OR NOT -- BETWEEN THE NEEDS OF THE STATE AND OF MOST OF ITS PEOPLE AND THE NEEDS OF THE INDIVIDUAL CITIZEN AND OF HIS OR HER FAMILY.

WHO, FOR EXAMPLE, IS GOING TO DECIDE HOW WE CARE FOR A CHILD WITH AIDS? IS THE WISH OF THE CHILD'S FAMILY THE MOST IMPORTANT WISH TO CONSIDER? THE ANSWER SO FAR SEEMS TO BE "NO."

WHO, FOR EXAMPLE, WILL HAVE THE FINAL WORD ON WHETHER OR NOT SOMEONE IN TERMINAL ILLNESS IS READY TO DIE? THE ANSWER HERE, ALSO, SEEMS TO BE MIXED. THE ISSUE WAS FIRST PRESSED IN UPON US MOST DRAMATICALLY BY THE QUINLAN FAMILY, WHOSE DAUGHTER, KAREN, WENT INTO A DRUG-RELATED TERMINAL COMA AND SURVIVED THAT WAY FOR MANY YEARS.

THE ISSUE TURNED ON WHETHER OR NOT A HUMAN BEING -- IN WHATEVER STATE OF CONSCIOUSNESS -- HAS A RIGHT TO NOURISHMENT AS LONG AS HE OR SHE CAN ABSORB IT. THE STATE OF NEW JERSEY SAID KAREN QUINLAN HAD THAT RIGHT. KAREN QUINLAN'S FAMILY DISAGREED -- AND LOST.

AND WHAT ABOUT THIS ISSUE AS IT AFFECTS THE ELDERLY? SURELY IT IS NOT BEYOND THE REALM OF POSSIBILITY THAT A FAMILY MAY ONE DAY BE FEATURED IN THE NEWSPAPERS -- AND BROUGHT INTO COURT -- FOR DENYING NOURISHMENT OR PROPER CARE FOR THEIR "GRANNY DOE."

WILL WE GUARANTEE TO "GRANNY DOE" -- WHO MAY HAVE LESS THAN A YEAR TO LIVE -- ALL THE SAME PROTECTIONS OF THE CONSTITUTION WE WANT TO GIVE TO "BABY DOE," WHO MAY LIVE FOR THE FULL THREE-SCORE AND 10?

LET ME REPEAT AGAIN THAT THE COST IN DOLLARS SHOULD NOT PLAY -- AND I BELIEVE WILL NOT PLAY -- ANY SERIOUS ROLE IN THE ANSWER TO THE "GRANNY DOE" QUESTION, DESPITE ALL THE SABER-RATTLING OF THE COST-CONTAINERS. WE'LL ANSWER THAT QUESTION IN THE FUTURE AS WE HAVE IN THE PAST, ON THE BASIS OF WHAT WE WANT TO BE THE PREDOMINANT PUBLIC ETHIC.

AT THE BEGINNING OF MY REMARKS I SAID THAT THE FRAMEWORK FOR THIS EVENING'S LECTURE IS GOING TO BE THE FAMILY, AS SUGGESTED BY THE PRESIDENT DURING HIS RECENT "STATE OF THE UNION" MESSAGE.

I THINK THE PRESIDENT IS ASKING US TO TAKE A SECOND LOOK AT THE WAY WE DECIDE MAJOR ISSUES OF HEALTH AND WELFARE -- OF LIFE AND DEATH -- IN OUR COUNTRY. HE'S PUTTING THE FAMILY AND ITS PERSONAL, PRIVATE ETHICAL SYSTEM BACK UP ON THE TOP RUNG, SO TO SPEAK.

MOST FAMILIES DESERVE TO BE THERE. MOST FAMILIES ARE GROUNDED IN A SYSTEM OF ETHICS THAT IS SHARED IN OUR SOCIETY. IT IS COMPASSIONATE, CHARITABLE, AND JUST.

BUT SOME FAMILIES VEER AWAY FROM THIS NORM, FOR REASONS THAT MAY OR MAY NOT MAKE A LOT OF SENSE, BUT WHICH NEVERTHELESS VIOLATE WHAT IS PERCEIVED AS THE NATIONAL NORM.

SOCIETY'S RESPONSE CAN SOMETIMES BE HARSH. WHETHER OR NOT YOU AGREED WITH THEIR VIEW, I'M SURE YOUR HEART MUST GO OUT TO THE QUINLAN FAMILY FOR THE CHILD THEY LOST TO FATE AND THE ETHICAL BATTLE THEY LOST TO THE STATE.

THERE IS MUCH ANGUISH AMONG OUR PEOPLE, AS, DAY TO DAY, THEY TRY TO SORT OUT THE QUESTIONS AND DECIDE WHAT IS ETHICALLY THE "RIGHT THING TO DO."

THIS ETHICAL CONTEST IS A VERY IMPORTANT ISSUE FOR THE AMERICAN PEOPLE. IT WILL BE DISCUSSED AND DEBATED LONGER THAN THE TERM IN OFFICE OF ONE PRESIDENT OR ONE SURGEON GENERAL, I WILL ASSURE YOU. THIS QUESTION WAS HOVERING IN THE BACKGROUND BEFORE THE ELECTION OF 1980 AND WILL CERTAINLY BE WITH US LONG AFTER THE ELECTION OF 1988.

THE WAY WE GROW UP IN AMERICA...THE WAY WE PREPARE FOR THE ADULT WORLD...THE WAY WE PUT TOGETHER OUR FAMILIES...THESE ARE THE EXPERIENCES THAT GUIDE US IN OUR MOST FUNDAMENTAL HUMAN RELATIONSHIPS.

THE PROCESS HAS ALWAYS SEEMED TO PRODUCE SUCH A DURABLE AND RELIABLE ETHIC FOR MOST OF US. BUT, AS EACH NEW PUBLIC HEALTH ISSUE APPEARS THAT HAS SOME EFFECT UPON FAMILY LIFE, WE UNDERSTAND JUST HOW VULNERABLE THE PROCESS AND THE ETHIC MAY BE.

THE QUESTION IS SERIOUS:

HOW DO WE MAINTAIN A PRIVATE ETHIC
IN MATTERS AFFECTING THE PUBLIC HEALTH?

I DON'T HAVE THE ANSWER. I JUST HAVE A SENSE OF THE SERIOUSNESS OF THE QUESTION.

I AM REMINDED OF A REMARK ONCE MADE BY A VERY WISE LADY, REAR ADMIRAL GRACE HOPPER, OF THE U.S. NAVY'S AUTOMATION COMMAND. SHE SAID...

"A SHIP IN PORT IS SAFE, BUT PORTS
ARE NOT WHAT SHIPS ARE BUILT FOR."

TO PARAPHRASE COMMODORE HOPPER, THE ETHICAL VALUES WE BUILD IN OUR PERSONAL LIVES...AND IN OUR FAMILY LIVES...CAN'T BE BERTHED IN THE SNUG HARBOR OF CONVENTION AND PREJUDICE. WE'VE GOT TO SAIL WITH THEM THROUGH ALL THE ROUGH SEAS OF DAY-TO-DAY LIFE.

AND WE'VE GOT TO STAY IN ONE PIECE.

THAT'S WHAT I CAME TO SHARE WITH YOU THIS EVENING.

THANK YOU.

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